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BIG SKY BEHAVIORIST

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MONTANA ASSOCIATION FOR RETARDED CITIZENS

HOLDS CONFERENCE

The Montana Association for Retarded Citizens held its annual conference in Helena June 9, 10 and 11, 1977.

Among speakers at the conference were Senator Tom Towe who presented an update of recent legislation affecting the mentally retarded; James Ellis, professor of law at the University of New Mexico; Merlin Kurth, executive director of the Wisconsin Association for Retarded Citizens; and Larry Wagner, NARC representative from the state of Washington.

At the Saturday night banquet Montana Governor Thomas Judge told 150 delegates to the 19th annual conference that Montana is a leading state in the provision of services to retarded citizens.

In praise of achievements made in help for the retarded, Judge said that the growth of services for the mentally retarded in Montana has been more rapid than in any other area of social services. The governor thanked the MARC membership for their role in promoting provision of these services.

Judge also presented awards for distinguished service in improving the lives of the retarded to Vonnice Koenig of Kalispell; Shirley Rammer of Great Falls; and JoAnn Willis of Helena.

Art Dehn, trainer at the Billings Sheltered Workshop received the MARC Job Placement Award from Governor Judge for his work in moving retarded employees from a sheltered work environment into normal employment.

The governor also presented the National Association for Retarded Citizens (NARC) Calendar Art Award to Walter Bryan of Great Falls. A painting by Bryan was chosen from among more than 5,000 entries to be one of 12 art works on the NARC 1978 calendar.

"C O N S E N T"

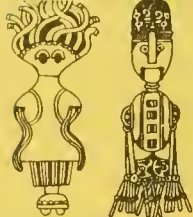
In 1973 the American Association on Mental Deficiency added to its purpose the reviewing and influencing of public policy which concerns the mentally retarded and those who work on their behalf. As the most recent effort to reinforce this decision the AAMD has published "CONSENT HANDBOOK" which deals with the problems surrounding the issue of "informed consent." The handbook suggests a framework for approaching consent issues and thoughtful procedures regarding informed consent. Information regarding purchase of the handbook can be obtained by contacting:

American Association on Mental
Deficiency
5101 Wisconsin Avenue, N.W.
Washington, D.C. 20016



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Report:



BSB READER SURVEY

A reader survey was included in the sixth issue of BSB and the results have been tabulated. Before elaborating on the survey results it must be pointed out that the survey elicited only a 9% response. In other words, approximately 9% of all BSB readers (59 respondents out of more than 600 readers) responded to the survey. Since the reader response was so limited all survey results must be digested with the following fact in mind: *information garnered from the reader survey is, in effect, a minority report.* However, the results are informative and interesting and worth taking note of. The results reflected below include only Montana respondents.

Question # 1: What is your current involvement in Montana's developmental disabilities system?

- 0% I am a recipient of DD services.
- 9% I work in a group home.
- 9% I work in a day program.
- 9% I am a client advocate
- 73% Other

In the "Other" category 29% were social workers, 29% were board members, 15% were county or public health nurses, 12% were DD council members, and 12% State employees. The remaining respondents in the "Other" category were parents, teacher/trainers, interested readers, ARC members, etc.

Question # 2: What type of training are you most involved in?

- 14% Self Help Skills
- 15% Independent Living Skills
- 13% Social Skills
- 10% Language Skills
- 13% Vocational Skills
- 22% Other
- 13% Did not respond



In the "Other" category 29% were involved in case management, 25% in health or nursing, 13% were not actively involved and the remainder were involved in parent training, preschool, coordination, staff training, advocacy, board training or acted as resource persons.

QUESTION # 4: What would you like to see more/any coverage of in future issues?

- 6% Individual Clients
- 15% Different Group Homes/Day Programs
- 9% Group Home/Day Program Staff
- 18% Montana State Policy
- 21% How to Run Different Types of Programs
- 13% Dear BSB Columns
- 11% Other
- 7% Did not respond

QUESTION # 5: Would you be interested in contributing articles in future issues?



- 5% Yes, I'm thinking about writing one now.
- 9% Yes, but I'd like you to contact me first.
- 4% Yes, but I'll need help deciding what to write about.
- 44% No
- 21% Other (Mostly that their contribution to developmental disabilities would come from other forms of participation)
- 18% Did not respond

QUESTION # 6: What person, group home or day program would you like to see an article about?

- 18% Specified a day program
- 16% A group home
- 13% A variety of articles
- 8% A sheltered workshop
- 45% Other

The "Other" category included such things as IHP's, training programs, legal rights and due process, the BRS&H group home and intensive training, new ideas, school programs, case management role, foster care, how-to articles and other items.

QUESTION # 8: Have you ever used the
DD HOTLINE?

- 6% Yes
- 23% No, I don't even know what it is.
- 17% No, I doubt you could help solve my problems.
- 38% Other (Most stated they had not needed to yet.)
- 17% Did not respond

QUESTION # 9: Do you want to continue
receiving the BSB?



- 0% No, please stop sending me junk-mail.
- 100% Yes, please continue by FREE subscription.

The BSB thanks all of you who took the time to respond to the survey. Every reader is encouraged to submit comments and suggestions regarding format and content of the BSB at any time.



REGION I DDD STAFF DISPLAYS COMMUNITY SPIRIT

In April the Region I DDD staff along with members of the EMI Activity Center staff and the Miles City Rehab supervisor participated as a team in "Almost anything goes." The fund raising event was held for the benefit of the Little Guy Hockey Association in Miles City. The team took first place in the tug-of-war and the saucer race and came in 6th out of 17 teams overall in spite of the flat tire on their wheel-barrow. BSB would be very interested in hearing from readers about unique fund raising events on behalf of the developmentally disabled. If you know of such an activity please contact us.

Book Available

Nancy Dodd from eastern Montana College recommends the following recent publication to our readers:

Educational Programming for the Severely and Profoundly Handicapped, Edited by Ed Sontag, Judy Smith & Nick Certo, Price, \$14.95

The book is published by the *Council for Exceptional Children* and may be ordered from:

1834 Meetinghouse Road
Boothwyn, PA 19061

EPILEPSY EXPLAINED

by

Dale M. Peterson, M.D.

Neurologist, The Billings Clinic

The word epilepsy refers to a group of disturbances of the brain for which a seizure is the major manifestation. A seizure or convulsion is an episodic event which has a beginning and ending in the stream of the individual's consciousness. It is of brief duration, usually less than 90 seconds. There may be impairment of consciousness, or muscular weakness which lasts longer. A seizure is an involuntary event such that the patient can neither bring it on nor stop it. The group of disturbances that we call the epilepsies have as their common mechanism a sudden excessive electrical discharge from brain cells which may cause excess or loss of muscle tone, movement, or a disorder of sensation or of the special senses. The symptoms that occur are determined by the area of the brain involved by the electrical discharge.

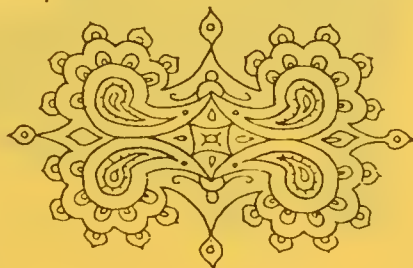
There are many causes of epilepsy and therefore many epilepsies. They are symptoms of some underlying alteration of the brain. This alteration may be structural (some change in the anatomy), chemical (some change in metabolism or chemical balance), or physiologic, which refers to alteration of electrical discharges themselves. All three factors may be combined. There are contributing factors to the development of epilepsy such as inheritance, trauma (either at birth or later), infection of the brain, high fever, toxic and metabolic disorders in the body, vascular diseases such as stroke or brain hemorrhage and various sorts of tumors. An individual may have seizures and no other evidence of brain abnormality. Other signs such as mental deficiency, paralysis, speech or visual disturbances may be present in individuals who have them.

An international classification of epileptic seizures has been agreed upon and basically they are divided into the types outlined. These terms replace older less exact terms such as "petit mal," "grand mal" and "psychomotor." We determine the type or types of seizures an individual has by obtaining a history of the attacks both from the patient and observers recording the events prior to, during and after the seizure, factors which are likely to precipitate them, their frequency and time of day. A medical evaluation of the past history, response to medication and family history are also important. Then a physical and neurologic examination is performed. Sometimes, laboratory work is necessary, involving analysis of blood, urine, x-rays and electroencephalograms.

With the above information in hand, the physician decides which anti-convulsant or anticonvulsants are likely to be most effective. The medication is adjusted in an effort to control the number of attacks as completely as possible, taking into consideration the fact that some medications may also cause toxic effects or side effects, which in some cases are more disturbing than an occasional seizure. These medications treat the symptom of seizure but do not alter its cause and occasionally there are disorders which have to be dealt with in other ways. In addition, the treatment of the seizure disorder and its implications must be clear to the individual's family and those caring for him. In recent years, the measurement of anticonvulsant levels in the blood has provided a help in treatment for patients with a difficult to control seizure disorder. Inappropriately low levels would spot an individual who is either not taking the medication regularly or not absorbing it properly, and detection of levels which are too high minimize the risk of side effects or sedation. Regular hours, a balanced diet and a stable environment are also important in minimizing the number of attacks. In

rare individuals surgery is of benefit. Most individuals with epilepsy are able to hold jobs, have families and live normal full lives. Exceptions to this occur either because of frequent attacks under poor control or the nature of the other conditions associated with the seizure disorder.

The question is often asked regarding what should be done if an individual is having a convulsion. There are a number of unfounded fears regarding patients swallowing their tongues or dying during an attack, but compared to the number of people in our society who are subject to seizures, the chance of bodily harm from the convulsion itself is minimal. Individuals who have a seizure with loss of consciousness and generalized violent muscular movements should be placed in a safe place where they are not likely to be hurt by objects around them. Usually, the floor or the ground is best. They should be turned on their sides, if possible, to allow any saliva or secretions to drain out, but no attempts should be made to put foreign bodies or the fingers into the mouth, since it is usually impossible to open the mouth, and the risk of injury to the patient or the helper is great. This often involves broken teeth and dental work or bitten fingers. After the seizure, the patient may be very confused for a time and it is of help if one person stays with him until he is once again alert. Ordinarily, people who are prone to these attacks do not have to be rushed to an emergency room after a solitary seizure, since usually by the time they get there, they are back to normal anyway. Patients who have continual seizure activity without regaining consciousness do need emergency medical care to protect their airways, administer parenteral anti-convulsant medications, and detect any precipitating factors for this repetitive seizure activity (status epilepticus).



A final word should be said regarding the Epilepsy Foundation of America. This national organization has units in major cities in Montana where members are willing to give advice to individuals with seizure disorders or those caring for them. This organization has as its goals: research, education, dissemination of information and support for special facilities. It has been active in professional education, community services, public health and public education. For more information please contact the chapter nearest you.

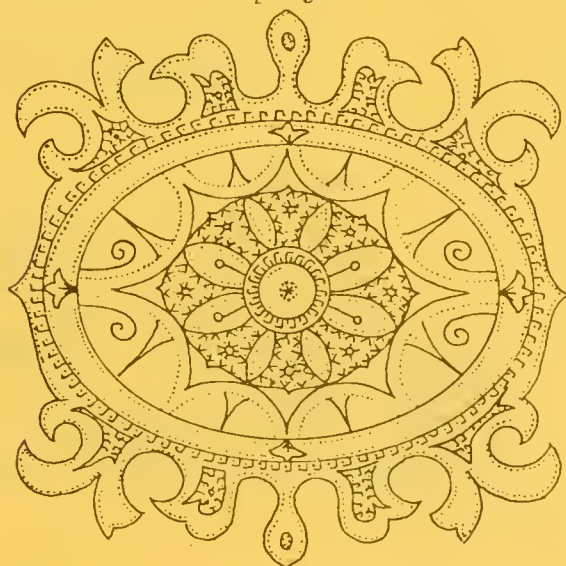
Big Sky Epilepsy Foundation
Box 1562
Billings, Montana 59103

Copper Chapter of Great Falls
4400 Central Avenue
Great Falls, Montana 59405

Butte Epilepsy Association
Box 3535
Butte, Montana 59701

Western Montana Epilepsy Foundation
651 South Fifth Street East
Missoula, Montana 59801

(Although the above information is common knowledge, the format of this presentation was organized from a tape slide program edited by Clark H. Millikan, M.D. and copyrighted by the Parke Davis Company in 1976.)



INTERNATIONAL CLASSIFICATION OF EPILEPTIC SEIZURES

I. Partial Seizures

A. Partial seizures with elementary symptoms

1. Muscular symptoms causing movement or speech (vocalization or arrest)
2. Sensory symptoms
 - a. Body
 - b. Visual
 - c. Hearing
 - d. Smell
 - e. Taste
 - f. Vertigo
3. Autonomic symptoms (gastric, bowel, urinary, skin color, pulse, blood pressure)
4. Combination of above

B. Partial seizure with complex symptoms

1. Impaired consciousness
2. Memory and thinking disturbances
3. Illusions and hallucinations
4. Automatic behavior
5. Combination of above

C. Partial seizures which then become generalized

II. Generalized Seizures

A. Absence

1. Simple absence ("petit mal") impairment of consciousness only
2. Complex absence - impairment of consciousness associated with other occurrence
 - a. Muscle jerks
 - b. Change in muscle tone
 - c. Loss of muscle tone
 - d. Automatic movements
 - e. Autonomic symptoms
 - f. Combination of above

B. Myoclonic jerks (sudden muscular movements)

C. Infantile spasms

D. Clonic seizure (repetitive muscular jerking)

E. Tonic seizure (sustained muscle rigidity)

F. Tonic-clonic ("grand mal")

G. Atonic (loss of tone)

H. Akinetic (loss of movement)

III. Unilateral or Predominately Unilateral

IV. Unclassified (because of incomplete information)



Let each
become all
he or she
is capable
of being

DDTI MONTANA

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BOARD OF DIRECTORS
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Marshall Cook
Warren Gardner
Art Kienas
Peg MacDonald
Lee Warren
Jerry Willis

Dear Providers, Clients, Regional Council Members, and
Concerned Persons:

The Staff and Board of Directors of DDTI would like to express our deepest thanks and appreciation for the support and cooperation you have provided us over the last year. Your hospitality and commitment to training have been a strong indication of your belief in community services for the developmentally disabled.

While DDTI will not carry out training activities for the Developmental Disabilities Division after June 30, 1977, the corporation will maintain itself for another year. We are presently seeking alternative funding bases. In addition, we will be doing everything we can to make certain that future state or regional training efforts are available to support the maintenance of community-based services. Since quality services for the developmentally disabled is of major importance, and training is a necessary and vital component in insuring that goal, we urge all of you to continue to express your training needs.

Again, please accept our heartfelt thanks for your support and we wish you success and happiness in your future efforts.

The DDTI Board of Directors and Staff

Any further correspondence should be directed to:

Sam Sunwall, Chairman
DDTI Board of Directors
Box 78 Star Route
Conrad MT 59425

CONFIDENTIALITY ISSUES



(NOTE: The last issue of BSB carried an article titled "Confidentiality Issues" in which a sentence was left out. Due to the accidental deletion the article was unintelligible. The following is a corrected version.)

Many persons have expressed concerns about the issue of confidentiality, both from the philosophical standpoint and from the pragmatic standpoint, e.g., "exactly who is authorized to see what information?"

Although there is no statewide policy on this matter of which we are aware, some general guidelines can be discussed. The most general rule one should use in determining access to information is that the person requesting information should be involved, directly or indirectly, in providing services to the client. This would not necessarily apply to family members however. In addition, this does not imply that a person involved in the

provision of services should have access to all client information. For example, it may be that a physical therapist would need to see physical therapy and medical information but not the social history.

Various research, needs assessment, and other investigations may require access to client demographic and programmatic information. If persons conducting such work have the proper authorization, this kind of information should be made available. The important consideration here is that the data are used in such a way that individuals cannot be identified.

A useful reference which readers may obtain by contacting the BSB is entitled, "Data Bases and the Privacy Rights of Mentally Retarded Persons", which was developed by the AAMD task force on data base confidentiality.

